



Home Care Resources

April 2016

1. Home Care Briefing - '*Looking after people with Myalgic Encephalomyelitis*'

Version I – Home Care Worker Briefing

Care Topics:

- Approach to Care
- Sensory Overload
- Protecting from Infection
- Shopping and Cooking

Management Considerations:

- Preparing Staff
- Continuity of care
- Use & Misuse of Mobile Phones
- Managing Infection Risk

List of Further Materials for Education & Awareness (*to be made available as a stand alone item*)

Version II – Home Care Delivery Briefing

This later edition covers similar topics, with *Guidance for Hands On Carers* presented in text boxes. As the title suggests, this Briefing is pitched at agency managers, social workers, and service commissioners. Relevant extracts from Chapter on 'People with Severe CFS/ME' from 'NICE' clinical guideline 53 are cited (*more on this at item 9*).

Originally published as pull out features from the centre of the Quarterly, the Briefings are presented in booklet format (4 sides of A4).

2. Pro Forma Letter for circulating the Home Care Delivery Briefing

3. Home Care - Key Messages

Basic grounding on the Care Topics from Home Care Worker Briefing

Two presentations are available, both on a single page:

- 3a.** 'Guidance for Hands on Carers' from Home Care Delivery Briefing II – this item has been used in
- 3b.** Simplest presentation – brief points listed under the care topics

4. How do I help someone with Severe M.E.?

Severe M.E. Awareness & Care – by Linda & Greg Crowhurst; *together with:*

How Can a Doctor Help Someone with M.E.? – by Dr Nigel Speight

5. Home Care - '*getting it right*'

Flagship article promoting this theme. A service user speaks eloquently about this topic including the consequences for patients when public services get care wrong, the implications for cost effective long term planning, and how to get the type of care delivery correct. She also touches on NHS Continuing Healthcare assessments (these usually involve a 'multidisciplinary team' from NHS and social services). A carer's insight is also presented, along with findings from 25% ME Group social services survey on Coping with Community Care Assessment process [see item 7 below]. Includes some key messages for home care workers & managers, respectively. Lists some further resources from 25% ME Group, and further materials for education & awareness.

Published Summer 2015 as a pull out section from the Quarterly Issue 39, marking Severe M.E.: A Day for Understanding & Remembrance on Aug 8th

Also on the Home Care Theme for Severe M.E. Awareness 2015:

Home Care & Severe M.E. On line article by 25% ME Group advocacy worker, published on the Phoenix Rising website. Can be read at: <http://phoenixrising.me/archives/27607>

Posters

- By Greg Crowhurst for the 25% ME Group: view under heading 'Severe M.E. Day 2015' at - http://www.25megroup.org/campaigning_Severe_ME_Day.html
- By Working for ME in Wales (WAMES): available as e-files from the 25% ME Group, or view at <http://wames.org.uk/cms-english/2015/08/severe-me-day-saturday-8-august-2015/>

6. Social Services, Care & 'Re-ablement' – 'just plain cruel'

Prompted by a consultation by the 'National Institute for Health & Care Excellence' on the scope of a guideline to be developed on '*short term interventions for regaining independence*'.

(NOTE: Title of the planned guideline changed to '*Intermediate care – including re-ablement*' following this consultation.)

Covers the 25% ME Group's input to this consultation, on behalf of people with severe M.E.

7. Social Services Survey Findings

Reports on findings from the 25% ME Group Social Services Survey, conducted autumn 2008:

- **Accessing & Receiving Home Care (findings in full)**
- **Summary & Overview of Findings**
- **Community Care Assessment Experience**
- **Occupational Therapy**
- **Family Carers' Experiences**

8. Meeting Care Needs (Scotland)

Report reflecting what members living in Scotland reported in a 2011 feedback exercise.

Also: **Your Illness and Best Management** – feedback on topics around management, particularly activity and rest, which may be useful to share with social services.

9. Clinical Guideline 53 – extracts on Home Care

Much of CG53 from 'NICE' is unfit for purpose with respect to a person with M.E. However there is relevant material in Chapter 7 – '*People with Severe CFS/ME*', which could be helpful with a view to accessing suitable, and suitably delivered, home care provision.

This chapter is only contained in the full version of the guideline, and begins on page 303. We consider it unlikely that many professionals will have read this far; also the full version of the guideline is no longer readily available. So we have highlighted this in the Home Care Delivery Briefing (as listed above). In addition, we can also supply a single sheet with the relevant extracts.

NB: Chapter 7 – '*People with Severe CFS/ME*' states: ... *this is not intended as a definitive guide to the specialist CFS/ME care needed for this patient group, and further reading is recommended.* The further reading recommended is:

Crowhurst G. Supporting people with severe myalgic encephalomyelitis Nursing Standard 1921; (21); P38-43 **Copies of this article are available from the 25% ME Group.**

NOTE: Greg and his wife Linda Crowhurst have produced further excellent material. For example:

Supporting Someone with Severe ME: Care Sheets

A Practical Guide to Supporting Someone with Severe ME

For copies see the 'Stonebird' website: www.stonebird.co.uk – 'the lived experience of severe myalgic encephalomyelitis'